Presidential Commission
for the Study of Bioethical Issues

TRANSCRIPT

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SESSION 2: PUBLIC HEALTH PERSPECTIVES ON THE CURRENT EBOLA EPIDEMIC IN WEST AFRICA

DR. WAGNER: All right, Commissioners. Let's—since our guests are ready to go, let's the rest of us also do that.

Delighted to welcome our next panel, and we'll use the same process as before. One by one, we will introduce you and ask you to speak, and then we'll introduce and move each successive—to each successive panelist and hold all questions until all three of you have had a chance to speak.

This session, we've asked our panelists to help us advise us on the public health perspectives on the current Ebola epidemic in Western Africa.

And we will begin with Dr. Peter Hotez. Dr. Hotez is Dean of the National School of Tropical Medicine and Professor of Pediatrics and Molecular Virology and Microbiology at Baylor College of Medicine. He also heads the new section of pediatric tropical medicine and is Texas Children's Hospital Endowed Chair of Tropical Pediatrics.

He's the President of the Sabin Vaccine Institute, is an internationally recognized physician-scientist in neglected tropical diseases and vaccine development. And in 2006, at the Clinton Global Initiative, he co-founded the Global Network for Neglected Tropical Diseases to provide access to essential medicines for hundreds of millions of people.

Dr. Hotez is an elected member of the Institute of Medicine of the National Academy of Sciences, and in 2011, he was awarded the Abraham Horwitz award for excellence in leadership in inter-American health. And in 2015, the White House and the U.S. State Department selected him as United States Science Envoy.

We're delighted to welcome you.

DR. HOTEZ: Well, thank you. Thank you for having me.

The best part about this morning for me is I'm sitting here with two of my real biomedical heroes, Dr. Gayle and Dr. Foege, and so that's a really special thrill for me that I'll remember for a long time.

What I'm going to do is give you—what I was asked to do is give a brief overview of the tropical infections afflicting the three West African countries beyond Ebola, and I think one of the sobering conclusions, the take-home messages from today, is Ebola may be the least of your worries.

Just to give you a framework, these diseases are handled under the sixth Millennium Development Goal to combat HIV/AIDS, malaria, and other diseases. One of the activities I'm involved with is to be part of the Global Burden of Disease study which is based at the Institute for Health Metrics at the University of Washington. Yes, that's half the list of authors. It looks like a paper out of the CERN Physics Laboratory. But it's a huge analysis in order to really assess the impact over the last decade or so of the Millennium Development Goals. And there's some victories.

Based on looking at the follow-up of the Global Fund for AIDS, Tuberculosis, and Malaria and the U.S. President's Malaria Initiative, it looks like the world has reduced the number of new malaria cases by 30 percent and the number of deaths by 30 percent. And I like to say that this is a pretty good advertisement of why overseas development assistance does work. It's had a big impact.

A subset of those authors have now looked at what we call the neglected tropical diseases, these 17 chronic and debilitating neglected infections that affect people living in extreme poverty, and the numbers are pretty remarkable. These are the least and the most

common afflictions that affect the world's poor, that affect about a billion. I like to call them the most important diseases you've never heard of, because most people haven't.

So this is the most common affliction of humankind, ascariasis, 819 million. It's an intestinal roundworm. Whipworm infection, hookworm disease, schistosomiasis, lymphatic filariasis—and I can say them faster than anybody—onchocerciasis, foodborne trematodiases infections, cysticercosis, leishmaniases, echinococcosis, dracunculiases, trachoma, Chagas disease, dengue, African trypanosomiasis, rabies, yellow fever, yaws, Buruli ulcer. And here's Ebola.

So basically, every single person who lives in extreme poverty has one or more of these diseases. And this is now some new numbers that we've put together to look at what's happening in the three affected countries, Ebola-affected countries of Guinea, Liberia, and Sierra Leone.

And at the bottom there is the percentage of the population affected by Ebola, and then there's everything else on top. And the bottom line is while we have 20,000 cases of Ebola, more than half the population of Guinea, Sierra Leone, and Liberia is affected by one or more neglected tropical diseases.

And I'd like to call your attention to the top three, schistosomiasis, malaria, and hookworm. Basically, every single person living in poverty in these three countries has one of these infections, and usually, they have all three. And the consequence especially is this combination creates this perfect storm of profound anemia and disability, and it's not always just death.

So one of the ways we express that is a disability-adjusted life year, and what you see for the 17 diseases, there's more blue than orange, and what that means is while some of them are killer diseases like Ebola, we're also getting profound disability. And that's not something that

gets to a quick sound bite on the news, and yet it could be equally important, particularly because it's linked to poverty.

So one of the things that we can show about these neglected tropical diseases in addition to being a public health problem, they're the stealth reason why the bottom billion can't escape poverty, the 1.3 billion people who live below the World Bank poverty line. It's also the reason why the poorest people in the three affected countries in West Africa can't escape poverty because they make people too sick to go to work. They actually shave IQ points off kids, and they impair intellectual and physical development.

They have a huge impact on the health of girls and women, so what I like to say is every single girl and woman living in poverty has one or more of these diseases.

I have pregnancy outcomes there, but it goes much beyond that. This concept of neglected tropical diseases promote poverty.

This is a new paper that Jennifer Herricks and I—Jennifer is a post-doc with me who's here in the audience. We've actually derived this interesting number. We call the worm index of human development, and we can actually show this interesting correlation. As the human development index goes down, your worm index goes up. And so the key is to show cause and effect which is something that we're working on.

So what are we doing about this? Well, we helped to design a few years back this package of medicines that's now being delivered through USAID, and it's an impressive program. USAID now has just treated its one billionth patient with this package of medicines that simultaneously targets the intestinal worms, schistosomiasis, lymphatic filariasis, onchocerciasis, and trachoma.

And USAID is certainly doing its part looking at those neglected tropical diseases. In two of the countries in West Africa, Sierra Leone and Guinea, and their British counterparts, the British Department for International Development, is also helping with Liberia as well. And that's having a huge impact to temporarily knock down some of the burden of these diseases.

And here's where we're at globally in terms of our coverage with this mass treatment package. We're doing pretty well with onchocerciasis, about 76 percent coverage globally. We're doing not very well with the intestinal worms, lymphatic filariasis, and we're doing terribly with schistosomiasis.

And schistosomiasis is something you need to remember because one of the things that our studies reveal is that there's a new link now between female genital schistosomiasis and HIV/AIDS.

So those of us who went to medical school or graduate school learned about something called urinary tract schistosomiasis, and it was called urinary tract schistosomiasis because nobody bothered doing a colposcopic exam on the girls and women with this condition.

And we now realize that about more than half of them have those same lesions in their cervix, their uterus, their lower genital tract. It's the cause of pain, bleeding, terrible stigma, marital discord. And now it's been linked to a fourfold increase in horizontal transmission of HIV/AIDS.

So this may be Africa's most common gynecologic problem that you've never heard of, number one, and number two, it may be one of the most important co-factors in Africa's AIDS epidemic that's not being dealt with at all. And so right now, we're not—we don't have programs for schistosomiasis incorporated into the Global Fund, into PEPFAR, and that's something that we need to change.

In terms of where we're at with elimination for these diseases, I think we feel pretty good about the role of mass treatment for advancing the elimination of lymphatic filariasis and trachoma, maybe for onchocerciasis. But this is a study of 400 experts who feel pretty strongly that we're not going to get there with mass treatment alone for intestinal worms and schistosomiasis.

And one of the things that we're working on in our laboratories is we've developed two vaccines that are now in clinical trials, one for hookworm infection, one for schistosomiasis, that we're hoping in time to combine. And we call them anti-poverty vaccines because we think they're not only going to have an impact on public health but reducing poverty as well.

So that's just a brief overview, and I'll stop there.

DR. WAGNER: That's fascinating. Thank you, Peter.

And we'll move next to Dr. Helene D. Gayle. She is president and CEO of CARE USA, a leading international humanitarian organization. She's an expert on health, global development, and humanitarian issues.

Dr. Gayle spent 20 years with the CDC working primarily on HIV/AIDS. She then worked at the Bill and Melinda Gates Foundation directing programs on HIV/AIDS and other global health issues. And she currently serves on many public company and non-profit boards, also, the President's Commission on White House Fellowships and the U.S. Department of State's Foreign Affairs Policy Board.

She's a member of the Council on Foreign Relations, the American Public Health Association, the Institute of Medicine, and the American Academy of Pediatrics. And she was named one of Forbes 100 Most Powerful Women and has published numerous scientific articles

on HIV/AIDS and other public health issues, received 13 honorary degrees, holds faculty appointments to the University of Washington and at Emory University.

Welcome, Helene. It's good to have you here.

DR. GAYLE: Thank you, and you didn't add in that, proud graduate of Penn, yes. Penn Med, so I got both universities covered. Also—

DR. WAGNER: I apologize. The record has been set straight.

DR. GAYLE: That's all right.

And like Peter, I'm also very honored to be here with both of my esteemed colleagues.

Just a disclaimer, everything I know is a result of Bill Foege, so if I screw up royally, it's as a result of him. If I do okay, it's also a result of him.

So thanks first of all for doing this, and it's great.

And I often call myself a lapsed physician because what I do now in my work today is really much more broadly about development, of which health is obviously a very important part of that. And so I'm going to talk more from the context of a development agency and maybe touch on a few issues in a slightly different light.

And one I think is kind of what are our broader ethical issues and obligations, then say a little bit about why communities and community response has been so important in this and lessons that we can learn more broadly, why it's important to involve different sectors.

We talk a lot about the health organizations and their role, but how do we think about this more broadly? And then a little bit about the social and economic impact that is very much a part of it, which is again from a development agency's standpoint, kind of where a lot of our focus.

And just to say and there will be plenty of time to get more into this, I think there are a lot of broader ethical issues that get raised in this, and I think we focus a lot on the immediate issues around Ebola trials and all of those.

And that's incredibly important, but, and I go back to one of your comments in the beginning, Jim, talking about how it is important for us to think of health globally because it is no longer locally. And I think that's incredibly true, and I think oftentimes for U.S. institutions, we think about this continuum of health and global health and how it impacts us.

But I also think we need to wrestle with what's the broader ethical issue of our responsibility to respond as a wealthy nation more broadly whether it has an impact on us or not. And I think of my many years at CDC where often we justified what we did in the context of how it would affect the U.S. population, and we know that diseases are global, but then how should we be thinking about our responsibility overall because all life has equal value, and what does that mean for us as a wealthy nation?

I think there are other ethical—kind of broader ethical issues to think about and wrestle with which is—Peter's talk alluded to it somewhat—that in the context of West Africa, is Ebola the most important issue, and how are we thinking about our responsibility to people who are in the midst of an incredibly important crisis but who are facing other issues, both health issues as well as broader issues, and how are we looking both at what we need to do immediately but not forgetting what the broader context is of communities in which we work.

And we saw on the ground women turned away who were pregnant, who died, because hospitals were filled with Ebola patients. Now, no one would say don't treat those Ebola patients, but what are we doing to think about the other issues that people on the ground face?

So just to say, I think there's a lot of broader issues ethically as we think about this epidemic.

The community response and why it's so important, and that's where an organization like CARE sits. We have been involved in at least two of the countries that were most impacted by the epidemic, Sierra Leone and Liberia, for decades. And it was incredibly important for a disease that had a huge amount of stigma where people were very likely to hide and not have trust—and again, thinking about the context, these are countries that had just come out of a civil war where there wasn't a huge amount of trust among communities with their own governments.

And thinking about what is the right role for outside governments, outside organizations to play in communities where there is a natural distrust. And again, I think we have a lot of parallels here when we think about Tuskegee and the specter of Tuskegee and what that has done to a lot of the ways in which we've responded.

And so I think thinking about how to involve and engage communities from the very beginning if we want to have the kind of public health impact that is so important. Our work largely in the beginning of the epidemic focused on things like engaging the community, raising awareness, bringing trust, making sure that people weren't—that the stigma that came with this was tackled appropriately and all the things that were so important if the more proximal work of treating patients was actually going to have an impact.

So thinking about more broadly, what's the context and what's the context in which these things happen, which is largely why there was an epidemic in these three countries where in many places, Nigeria a good case in point, but even in earlier epidemics, the epidemic didn't evolve in the same way. And so what's the context? And if we're not thinking about the context and how we engage communities, we're not going to have the appropriate response.

Important role of different actors in different sectors. And I'll just give the example of our organization which we focus on health but much more from a preventive and community-based approach, we're pushed by many to think about being direct care providers. And we have examples of some of our colleague organizations who felt very strongly that in order to get in the game, it was important to start looking at the more direct medical response, and they weren't effective in it.

And I think thinking about what's the right role, who are the right actors, what's the role of the government, what's the role of the NGO community, what's the role of direct health providers and making sure that there's coordination of those efforts along the way.

And then finally, the issue of social and economic impact which is where we've put a lot of our focus. Early on, I think there wasn't enough attention paid to what the downstream impacts of this were going to be. For a disease that is based in people—that part of the response is making sure that people don't congregate, everything that people do—whether it's attendance for school, ability for farmers to go and farm their crops, the ability for merchandise to get in so that basic needs were available for people—all those things were disrupted, hugely disrupted in countries that have had longstanding social and economic challenges coming out of a war.

And so now those very impacts whether it's schools that are in disrepair, children who have been out of schools for months, hospitals that are further fragmented and health care systems further fragmented, basic food and basic supplies, all those things that were disrupted that I think we also have to think about what are some of the downstream impacts and are we as a donor nation particularly thinking about how we don't walk away from all of the things that we know these communities are going to face and ultimately looking at what are the long-term

implications, including on the health care infrastructure if we don't want to see another Ebola-like crisis.

And to several people's points earlier, I think if we're not thinking about all of these things now, we're not going to be able to be prepared for whether it's Ebola or the next health crisis that has impact on health. Weak health infrastructures but also broadly has a huge impact on societies and on economies that will ultimately continue to breed these sorts of severe crises as they come along.

So just some thoughts from the perspective of an organization that's focusing on this kind of broader community approach.

DR. WAGNER: Thank you. We'll look forward to getting back to follow up on some of that.

Bill Foege is next. Dr. William Foege who began as an epidemiologist working in a successful campaign to eradicate smallpox in the 1970s. He was appointed Director of the CDC in 1977. Dr. Foege and several colleagues formed the Task Force for Child Survival in the 1980s, now the Task Force for Global Health, which was a working group of the WHO, UNICEF, the World Bank, and the United Nations Development Program, and the Rockefeller Foundation.

He joined the Carter Center in 1986 as its Executive Director, Fellow for Health Policy and Executive Director of Global 2000. In 1997, he joined the faculty of Emory University where he is Emeritus Presidential Distinguished Professor of International Health at the Rollins School of Public Health at Emory.

In September of '99, Dr. Foege became Senior Medical Advisor for the Bill and Melinda Gates Foundation, and he retired from there in 2001.

Dr. Foege has championed many issues, but child survival and development, injury prevention, population preventive medicine, and public health leadership are of special interest, particularly in the developing world.

He is a strong proponent of disease eradication and control and has taken an active role in the eradication of Guinea worm disease, polio, measles, and the elimination of river blindness, onchocerciasis.

By writing and lecturing extensively, Dr. Foege has succeeded in broadcasting public awareness of these issues and bringing them to the forefront of domestic and international health policies.

He has received many awards, the Lasker Prize, and most recently, the Presidential Medal of Freedom in 2012.

It's good to see you again, Bill. Thank you for being here.

DR. FOEGE: Thank you, Jim.

The first two-thirds of this panel has been so rich that I have to apologize already for the last third.

The thing we heard this morning about studies and placebos brought to mind—and so I'm going to do a quick aside—1953, Jonas Salk did not want to have a placebo group in the field trial of polio vaccine. His point was, I know it works, it would be unethical to have some children get a placebo.

His mentor Tommy Francis, a virologist from the University of Michigan, said that's not the way science works, and so Tommy Francis took on doing the field trial. He assembled 20,000 medical personnel, 60,000 education personnel, 200,000 volunteers, and 1.8 million children.

And in two years' time before computers, he was able to follow what happens with polio vaccine. April 12th, 1955, he had a press conference at the University of Michigan, and in three words, he summed up the two years, "safe, potent, effective."

Now, on to the question of what does public health have to do ethically with what's happening with Ebola. All through medical training, you keep hearing the words "do no harm." It's drilled into you.

What I did not realize at the time was almost every time that phrase was used, it was talking about an error of commission. And it wasn't until 50 years ago when my then-boss sent me to Africa to run a medical center, and his final words to me were, "By the way, you'll never forget the people you kill."

And that just kept going through my mind, and then I realized, of course you forget them because you kill far more people, cause far more damage by the things you don't do, by the science that you don't apply, the science you don't share, the vaccines you don't use, the inequities that you don't pursue.

I think that the single biggest biomedical ethical battleground of today is found in budgets. Budget people do not see themselves as ethicists. Ethicists don't like to spend time on budgets.

But Michael Osterholm from Minnesota said, "One of the best fire departments in Minnesota is at the airport. It's almost never used, but no one would consider reducing funds."

So he asked, why do they continue to reduce funds for public health and prevention?

And the reason is because none of us as individuals, as a country, as a globe actually take health seriously until we lose it. And then we're always behind the curve.

So our anemic funding to WHO is part of the problem that we are now seeing. And WHO has been criticized with the Ebola outbreak, and we have to remember that we have been largely responsible for that by not funding them adequately.

The United States recoups every three months its total investment in smallpox eradication, every three months. And so we save more because of smallpox eradication than our dues to WHO. We've now recouped our investment 140 times.

We have significant problems funding prevention programs for many reasons. Health care delivery usually gets tested on a cost-effectiveness analysis while prevention is taken to a cost-benefit analysis. You have to show that you're not only doing something about the disease but you're saving money on top of that. It's not the right measure.

Dr. Jim Marks at the Robert Wood Johnson Foundation has pointed out that if you evaluate a U.S. government health program, you cannot look at benefits beyond 10 years because of the discounting of money. Well, if you give a child a measles vaccine, I can tell you those benefits go on for 60 and 70 years. If you keep a child from beginning to smoke, it's a lifetime. So it's not measured by the right indices.

When I started in global health, there were over three million deaths a year from measles, and we think of that now as we are looking at this country. At that time, measles was the single most lethal agent in the world. There were things that caused more death such as diarrhea or respiratory disease, but they were made up of a number of different agents. But measles was the single most lethal agent.

The deaths went down from three million to two million to one million, and they're now at 10 percent or less of where they were when I started.

A third ethical dilemma results from our global health efforts being dysfunctional. And back to our role with WHO, it was almost 70 years ago that WHO was being formed, and we insisted on strong regional offices in order to protect the Pan American Health Organization. So the regional offices of WHO have become so strong that they can undercut the director in Geneva any time they want to, so you don't actually have a unified system.

At the beginning of Ebola, there was, in fact, a fight between Geneva and the African regional office, and CDC was not invited in the midst of that fight.

But our own global health organization in this country is dysfunctional. The location of USAID in the State Department will always make politics a factor in health funding.

An ethical approach might be to have one person in charge of health whether it's domestic or global such as the Secretary of HHS so that all domestic decisions take into account what's happening globally, all foreign decisions take into account what's happening domestically.

Response, that's another area of omission. It's related to but separate from funding and organizational structure. In the response capacity, WHO simply doesn't have the kind of response that it needs.

In this country, over 65 years, we've developed the Epidemic Intelligence Service at CDC that responds to epidemics. WHO doesn't have something similar. But in 1982, the then-Secretary of HHS, Richard Schweiker, offered to WHO that the U.S. would help fund and organize an EIS program for WHO, and he was turned down. And several attempts since then have also met with no success.

The African Union as late as last weekend has now voted to establish an African CDC, and this might turn out to be a very effective and efficient way to improve what happens in Africa in disease outbreaks.

Another problem is the failure to think long term. By and large, we think of five-year objectives, and while much of what we do actually borrows from the future and causes environmental problems, disease eradication allows to make a contribution to everyone that follows us. I mean, it's just such a nice concept.

And except for bioterrorism, I can tell you that the world will never have to worry about smallpox, but last century, WHO said 300 million people died of smallpox.

Another problem, and Peter brought this up, is our tolerance for poverty. This is the single biggest reason for poor health in this country and the rest of the world. I see poverty as the slavery of today. We all get our food, our clothes, our lodging cheaper because poor people are subsidizing us by working at subsistence wages. It's no different than a southern plantation 160 years ago, and we could use Ebola to help make the case against poverty.

And finally, Richard Feynman, the physicist, said that, "Science has no power in itself. The power comes from its use."

Epidemiology has no power in itself until it's used and the same with compassion, the same with ethics.

Roger Bacon, a Franciscan, in a report to the Pope over 700 years ago said that, "Science has no moral compass."

And so this Commission can make sure that scientists have a moral compass even if science itself is neutral.

As a society, we have trouble grappling with the issue of health equity both domestically and globally. Our system is dysfunctional, and yet we give advice to the rest of the world on how to deliver health. Politicians can brag about our health care system and they do, but until Obamacare, we had 50 million people without health care insurance. And those 50 million people knew they were second-class citizens.

Gandhi said that his idea of the golden rule is that he could not accept what is not available to everyone. Our health care system would improve tremendously if politicians were forced to get average health care and not tax-supported exceptional care.

Consequential ethics would ask whether it is even ethical to have the marketplace in charge of our health care system or whether that already puts the focus on profit rather than health outcomes. If not ethical, how could we change it?

We spend more per capita, as you know, than any other country, and we don't even rank in the top 20 countries of the world when it comes to health outcomes. So even on an economic level, what we're doing isn't working. And it's certainly not working on an ethical level, but we give advice to other countries as if we knew what to do.

And I return to where I started, "do no harm." It's a powerful statement now degraded to say, "do no harm, unless money's involved."

I'd like to thank you for allowing an old man who has no career ambitions to state what he regards as the truth. Thank you.

(Applause.)

DR. WAGNER: Bill, thank you. That leaves the rest of us in a pretty pitiful place to follow.

So let me let the rest of the group off the hook and open with a simple question. How is that? Actually, all three of you struck these notes about poverty and also the broader concerns and the diseases—of diseases in the region. And that's what we're talking about in this session in particular is West Africa.

I have a question about the importance and what's incumbent upon this committee as it makes its recommendations about generalizing what we learn or what Ebola has helped us to focus on.

So Peter and Helene in particular with this one, do you folks have concerns that we might miss important ethical considerations about the kind of research—and we are focused mostly on—we are charged to focus on research ethics—that we would miss important ethical considerations by using only Ebola as our example?

DR. HOTEZ: Thank you for that question, and I'm still thinking about Bill's comments and Helene's, fantastic.

A couple of things, I think the problems that we saw—three issues that I'd like to bring up, if I can have the time. One is the role of conflict. The neglected tropical diseases, I helped make up the term, it's a bit of misnomer, quite honestly, because we call them "tropical." Tropical is a piece of it, but they're really diseases of poverty, but they're also diseases of conflict.

And one of the reasons why we saw Ebola take off in West Africa was these are countries that were reeling from a decade or more of internal and international conflict.

And one of the things I'd like to say is Ebola is really version 3.0 of what we've been seeing for the last 50 years which is that many people don't realize it, but this is not the first time we've seen massive disease rise out of conflict. We saw it with sleeping sickness in Angola and

Democratic Republic of Congo where 300,000 people died every year for more than a decade, but it went unseen because there were no journalists there. Or we saw it in kala-azar in the 1980s and 1990s where 100,000 people perished in the middle of the conflict by being exposed to sand fly bites and ultimately dying from that leukemia-like illness which is an infection.

One of the things I'd like to say is it would be nice if for once the world could be proactive in this. When you see an area of extreme conflict, to recognize that a horrific infectious disease, tropical disease outbreak will surely follow.

And one of the things I've been talking to the White House and State Department about is I think one of the next shoes that's going to fall is the Middle East and North Africa. ISIS occupied Syria and Iraq, we're already seeing refugees pouring across the border into Jordan and Lebanon and Turkey. We're seeing rabies. We're seeing huge amounts of leishmaniasis. We're going to see Middle Eastern Respiratory Syndrome.

We've got to build capacity to get ready for the next big thing that's going to happen in the Middle East and North Africa.

The second point that I'd briefly like to make is the interventions, not having an Ebola vaccine. The technology to make an Ebola vaccine was published—the two vaccines that we have out there, the adenovirus and the VSV vaccine, that was published in 2009 and 2010. So it basically laid there on the shelf for five to 10 years before finally, there was enough public pressure to get the big pharmaceutical companies to invest in it.

It's not unique to Ebola. Every 17 of those neglected tropical diseases has a major intervention that's sitting there because we have market failure. So what's happening is our technology has outpaced our political, our social our economic institutions to figure out how to advance those.

We're doing it on a small scale through the Sabin Vaccine Institute and our product development partnership, but it's—but the funding is extremely modest. We need to figure out a way to incentivize, and we could talk more about that.

And finally, one of the other things I'll say is Ebola has been really good for my TV career, and I've been on television almost every day in the month of October. And one of the things I would always say to the journalists was, "Aren't you worried about the Ebola virus coming to America?"

And I'd say, "No, I'm not worried at all about Ebola virus coming to America, but I am worried about 12 million Americans who live in extreme poverty with a neglected tropical disease."

And the answer was always, "Well, thank you, Dr. Hotez. We're out of time."

So we've got this undercurrent, as Bill eloquently points out, of extreme poverty and disease that we're not addressing here in the United States.

DR. WAGNER: Thank you for that, and those are all very helpful frame-setting points.

But I have a really very specific question. We do have the world's attention and America's attention with Ebola right now, okay, and we don't have it with schistosomiasis or lymphatic filariasis. But we do have the attention. We do have money coming into the system.

My question is, do you have comfort that we can actually lay down some of the ethical groundwork for the broad array of neglected diseases, let's call them that, which have such a cost in human life and misery, and also a risk, as we said earlier, to be global diseases, will we be—is there—I just want to know if you're comfortable, hey, take advantage of this Ebola situation and in doing so, we can lay the groundwork that will be broadly applicable, or do you say, gee, I wish you'd look at another disease? Do you get it?

DR. GAYLE: Well, just to add because I would agree with the points on particularly conflict and being able to know a little better where the next Ebola is going to strike, and I think we could get better at that.

But I do think that we have a moment and we should be opportunistic. And the reality is while we all realize that Ebola is never going to be a major problem here for the United States public, because we had a few cases, it raised the specter. That's why people became interested in what was going on in West Africa.

And I think look at it not dissimilar from the time, the many years I spent working on HIV and AIDS. I cared deeply about the HIV epidemic. I thought it was incredibly important as a singular public health issue, but I think more broadly, the money that we mobilized not only here in the United States but also PEPFAR and all of those incredible resources that we mobilized has had a huge impact on the health infrastructures, weak health infrastructures, globally like nothing else has.

And so I think we should take that two-plus billion dollars, use it for Ebola, but use it in a way that paints the roadmap for a longer term response because ultimately, this is about how do we make weak health infrastructures able to deal with the array of issues, not just how do we focus on Ebola. How do we get this, and how do we finally get people to think about preventive health and strengthening infrastructures?

When you talk about infrastructure strengthening by itself, people's eyes glaze over, but when you say Ebola or HIV or malaria, you get people to focus. And we can use that money in a much smarter way to think about how does it bolster the infrastructure.

DR. WAGNER: Amy.

DR. GUTMANN: This was a terrific panel, and I see Bill wants to say something. And my question is going to be to Bill and all of you, but I'm happy for you to begin by answering it.

Bill, you said many things that are really important to take to heart and for the public to know and take to heart, and I want to focus on one of those because we are—Ebola is a case study for us of lessons for public health, right, and what we can do with policy and attitudes toward public health.

So Bill said something that I want to say the converse of and see whether as a Commission we can run with as a theme of Ebola in this report.

Bill, you said we don't take public health seriously until we lose it. So I want the theme of our Commission to be we need to take public health seriously before we lose it because measles is an excellent example of how if you take it for granted and you stop doing what you need to do, you lose it.

And Bill also said something else which I think is incredibly central to the practice of medicine at its best and that's at its core which is errors of omission in medicine aren't as important as errors of commission. We lose lives when we don't do things, and they're equally ethically and practically bad as if we do things that are the wrong things.

And so I think, if you will, my question to you, Bill, is do you think as a bioethics commission we can run with, we need to take public health more seriously because if we don't, we will lose and we are losing lives to the extent that we don't, or as the converse is we need to take public health seriously before we lose it.

DR. FOEGE: Absolutely, and I think you should make the most out of Ebola despite the fact that there are bigger problems. And I always tell students that one of our jobs is to figure out

how to tie the fears of the rich to the needs of the poor. And Ebola has become a fear of the rich, and so I would use that to the maximum.

I think it also gives a chance to relook at the—

DR. GUTMANN: It's real. I mean, we're not making the fear up.

DR. FOEGE: That's right.

DR. GUTMANN: And the fear of measles now is real where it wasn't a few weeks ago.

DR. FOEGE: Exactly. I think Ebola alone allows us now to relook at the structure of WHO and ask what did we learn in 70 years? How would we like to have been put together if there were no political constraints? And having pictured that, how close can we come with the political constraints?

And then I would take it to one more step, which is, Will Durant once commented on how this country came together in the 1940s, and he asked the question, "Is it even possible for the world to come together?"

And his conclusion was, "No, unless the world feared an alien invasion."

But what we've seen over the years is we have surrogates for an alien invasion, and Ebola is one because we all feel at risk and therefore, we're willing to do something.

But health in general could be a surrogate for alien invasion as could global warning, and so Ebola could be a step in a surrogate.

DR. GUTMANN: Just one follow-up because to do this, we have to go from the concern, fear of losing one's health, to the facts of what works. And so you also gave the example of declaring with regard to the polio vaccine, it's safe, it's potent and it's effective.

How—and I ask this for all of you. How do we as a Commission maximize in our recommendations and our reasoning the importance and the—what are the levers for when we do

know it's safe, it's effective, and it works or we have the possibility of figuring that out, how do we communicate that effectively to a public and politicians who are all too—politicians I'll focus on because I—are too eager to go with the fear rather than with the facts.

DR. FOEGE: Well, Helene is our spokesperson on that.

DR. GAYLE: Okay. Well, I guess I would get back to how do you influence politicians to begin with. I mean, I think some of it's the facts and the information, but a lot of it is their constituents.

And how do you—I think that getting information to people is extremely powerful, and when I think about the—Ebola specifically and communities that we work with, it was by engaging with communities that we were able to get politicians, often, to be moved to action. So I think a lot of it is yes, we've got to focus on their politicians directly, but I think having people engaged and people believing that this is the truth and this is what we want, this is what we're holding you accountable for, is the way that we're going to make this happen.

DR. HOTEZ: I agree with everything everyone is saying, but I also want to say that we have to be careful not to be so broad and so general and simply say public health that people lose the message.

What I would like to see is to say Ebola is a case study of a disease of poverty and conflict, and the point is there's a couple of dozen diseases of poverty and conflict coming down the pike and we need to address all of those diseases of poverty and conflict both with building up infrastructure at WHO, both with figuring out new ways that we're going to do product development for all of these diseases and everything that goes with it. And that will put some kind of context and some simplicity around it.

DR. WAGNER: That helps a lot, as a matter of fact.

Nelson.

DR. MICHAEL: This is a comment, it's probably largely aimed at you, Helene, and it stems from our recent observations of what's happening in our own country with measles, what certainly has happened episodically in Clement's country and others with polio where the concern and fear of the disease itself becomes overwhelmed by the concern and fear of ordinary individuals that live in poverty about the intent of public health responses and the distrust not only of their own governments but the very visceral distrust of governments that have legacies that are unpleasant.

How can we connect those dots?

DR. GAYLE: I think it's difficult, but if I look at both examples here in the United States as well as our work internationally, I think again—and it sounds simplistic, but it is involving communities directly. And I think we have—I think we do a better job of that internationally than we do here in our own country.

And when I look back at the HIV epidemic, it was a turning point when CDC developed a program that focused on directly funding minority communities to work on the issues of minority HIV. And when it was the government, we're here, we're the government, please trust us, it didn't work. But when you had people who came from those communities talking to people in the ways that they were comfortable and had the messenger be as important as the message, I think that's when you actually make a difference.

And so in our work in Sierra Leone and Liberia around Ebola, it has been the communities that we have been working with for years, the communities that we do education programs, where we do microfinance programs, where we do agricultural productivity programs,

so they already trusted CARE and partners that we worked with and it's not just CARE. It's organizations more broadly that work with communities.

We weren't just there for Ebola. We weren't just there because there's this disease that Americans now care about and we're sending in our troops and we're sending in our money, but you've been there for the duration. So I think it is really how do you actually go to communities, ask them what their concerns are and then build a response around that that you have the most success.

And we're seeing that with work with the HIV vaccines where we're trying to get more minority participation in the trials who otherwise worried about vaccines being the cause of the disease. Again, I think there are lots of examples of, by working with communities and having the messengers be trusted messengers, that you start to build a response.

DR. WAGNER: To some extent, Nelson asked my question. I just wanted to maybe sort of correct our language a little bit, that the randomized controlled trials like the Salk one actually show that the vaccine is safe, potent, and efficacious.

And part of what we're talking about here is effectiveness, right, which involves both the building up of an infrastructure and addressing questions about culture and beliefs and trust between government and peoples as well.

So part of what Nelson was asking about was just trust in government. I was just going to ask more generally about whether there's anything new in the public health world to address the sorts of problems with rumors and beliefs that are deeply a part of culture which has affected the polio vaccine trials in a way that didn't for smallpox and also seems to be affecting our ability to eradicate measles even in this country.

DR. FOEGE: If you tangle with culture, culture always wins. But there are some examples now of what Helene was talking about.

Northern Nigeria is a good example because of the polio, and there were concerns that the polio vaccine had different things in it, HIV or estrogens and so forth. But part of the solution was actually suggested locally. Their vaccine was made then in Indonesia by Muslims, and that changed it. So it's not a solution that would have easily come from some of the rest of us, but that changed things.

Then the son of the emir who had started those rumors started working for the polio program. So again, this is the local accommodation.

In this country, I used to live on an island, Vashon Island, that was written up in the New York Times because it had the worst immunization record and because there were a lot of—it was an old hippie community where people did not trust government. They simply didn't get their children immunized.

What changed there was nothing that the government did. It was parents who had immunized their children started having meetings and inviting the other parents. What is it that you actually object to? So again, it was a local solution, and the immunization rates have gone up there.

DR. GUTMANN: There's good social science evidence now to underscore this, that the most effective way of influencing and changing opinion is by trusted acquaintances, neighbors, friends. That—and we've got to build on that.

DR. ALLEN: Thank you, Bill, for your remarks which I thought were incredibly powerful. And in the context of them, you referenced Gandhi, and you also stated that to tolerate

poverty is equivalent to slavery, that tolerating poverty is the slavery of today. It's like you said, a southern plantation.

So I want to just comment on that because given the way we in the United States think about poverty, we don't believe that—"we" meaning the culture as a whole—does not believe that people have a right not to be poor. We think that there are limitations on what the community as a whole is obligated to do to address other people's wants and even their suffering.

On the other hand, we can all agree that these diseases do have a connection to poverty. So I'm wondering, is it possible to decouple the case for aggressive public health interventions and public health education from the more general concern that those of us ex-hippies have with the eradication of poverty?

I would love to see poverty eradicated, but I believe that if I go out into the world saying let's get rid of poverty, it's going to be in a way a distraction from what I really want which is—I think it's possible is let's give everyone access to health care, everyone access to public health information, everyone educated about public health.

Do you see what I'm getting at? So can we decouple the general concern we all have—many of us have as liberals and as human rights advocates for poverty from the immediate need to get some public health interventions and public health education in place?

DR. FOEGE: It's a very good question. We should not wait to change poverty before we improve health because health itself is an anti-poverty measure. So you have to do these in parallel tracks.

But I think that your leading remarks, people think you're poor for some reason, that it's your responsibility. It's your fault, and that we don't see that this is actually a bad barrel rather than bad apples and to use the Lucifer Effect book.

And so the Marguerite Casey Foundation spends all their time on anti-poverty measures, and they are now coming up with the idea of a membership organization. You don't have to be poor to belong, but you have to—if you belong, you want people to go up the ladder.

And this membership organization may give enough power to poor people as the AARP has done to old people. It may give a new way of approaching this.

Wang Xi, six centuries ago in China said that, "Poverty should be seen as drowning. There's not a moment to lose. You have to fix it." But you have to do it in parallel tracks.

DR. GAYLE: Just to add to that, I think it's like any good marketer knows, you target your message and you segment your audience. And I think that some of this, it is how do you use health as a way of getting into addressing inequities that go beyond health, and then for some, it will be poverty and how does including health help your mission in poverty.

And I think you're right that for some, it isn't the poverty message, it's the health, but it will help poverty. And so at the end of the day, I'm more concerned and I think all of us are more concerned on what's the result, how do you segment the messages so that they get to the right audience and they're hearing it and they're not blocking it.

And if we can do that effectively and be opportunistic about how—whether it's the health or the poverty that we use, I think we can have the same outcome, and I think there are times when we have to fight our urge to want to put all of the issues out there when we know that by doing that, it's going to block and people aren't going to—the listener's not going to hear it, and

ultimately, we want to make sure we have messages that people are going to hear so that we can get the outcomes we want.

DR. HOTEZ: I think it's just—very quickly add, the numbers are there. We now have numbers to show that if you get rid of river blindness, onchocerciasis, from a community, how the economic level goes up dramatically. And we actually have numbers of return on investment. We have it for lymphatic filariasis. We have it for trachoma. We have it for about at least a dozen diseases.

The numbers are there. It just needs to be collated and presented in the right way.

DR. GUTMANN: Just so we know the problem, we have it on education in this country too. That in itself, I mean, we need to get it out, and we need to focus on what our mission is. And it will have ripple effects, but we shouldn't be ourselves blind to the earlier point of how to get that message out effectively with people in different communities who believe it, which we're all in agreement with because we've got to get both the facts and the effective communication out there.

DR. WAGNER: Final question, John.

DR. GAYLE: Could I just—sorry. But just to add to that point, I mean, I think we've all probably heard in different ways these studies that go out where you ask the American public how much would you spend on foreign assistance and you ask them how much do you think we spend, they think we spend a quarter of our budget on foreign assistance. You ask them what should we spend. They say about 10 percent. And you tell them what do we spend. It's less than one percent.

But if you ask people should we be spending money to make sure that children around the world don't die of preventable diseases, they all say yes, we'd be willing to. So again, just to

your point, that I think it is how do you frame it for different audiences, and there's really good data that suggest that dying people does make a difference to most people and feel like that's a good value for money.

DR. ARRAS: Thanks to all of you. A really enlightening panel.

We've heard it said eloquently and often in this room today that the time to think about the kinds of ethical issues we're going to encounter in public health emergencies is way before they happen. And I think that's true. And it's also been said that we generally don't take health seriously until we lose it.

And so we're confronted with all kinds of examples of like WHO being starved for money until something like Ebola happens, and then everybody complains about how ineffective they are.

In the health policy literature, we talk about the rescue principle a bit, this notion that we'll do anything to save a child in the well. This is what Helene was just talking about. We'll do anything to save that child in the well, but we won't really do anything to build a fence to prevent other children from falling into it.

So my question is have folks like you who think about these issues all the time, have you come up with ways to think more profitably about how to change that? Because I'm just wondering if we're just sort of bumping up against a kind of immutable psychological law that people just can't wrap their heads around the future in this way, right, or they're just hard wired to take emergency treatment seriously but not prevention.

So in the course of your work, have you come across creative, interesting ways to approach that problem?

DR. FOEGE: Well, I think of a high school coach by the name of Hugh McCabe who died at age 50 of lung cancer. He spent the last year of his life trying to convince high school students that it's not the last pack of cigarettes that kills you, it's the first one. I mean, that's the kind of thinking we have to get into this.

And when I've done some vocational guidance seminars for students, I always have them start by writing their obituary. What is they want people to say about them when they die, and then what do they have to do in order to get them to say that? Then what kind of skills do they need and so forth, so work backwards.

That's the kind of thing we have to do is be able to describe the last mile and then work backwards.

DR. HOTEZ: I would just like to say I think we have done it to some extent, right? I mean, the world did change in 2000. We launched PEPFAR. We launched the Global Fund. We launched the NTD campaign.

And now we've got the metrics, so we've published now the whole impact of Millennium Development Goal six. They're incredible victories, which is reinforcing things. So things have changed, but it's keeping up the momentum and keeping things with the sustainable development goals. And we'll see what that looks like and whether that's going to be effective.

DR. GAYLE: Yes, and I guess having spent most of my life trying to get people to be excited about non-events which is what prevention is, I do think that we have to be realistic. It is much more difficult to get people to care about something that they're preventing versus something that you can change.

And even PEPFAR, it wasn't until there were pills to put into people's mouths that people—that the money really came. It wasn't for the prevention which we had been screaming about forever. Now, it was wrapped in there.

And so I think again, part of it is how do we take things like this and be opportunistic about them to use them in a way that strengthens public health, whether people realize that that's what we're doing or not.

And then I think the other thing is how do we get other allies beyond health people talking about it, and so I think that the fact that corporations are now entering into the game because they realized that having fewer sick workers means less turnover and less need to have to retrain new workers. I think the fact that economists are starting to talk—have started to and on the WHO report about 10 years ago or so that looked at the economic benefits.

I think broadening it beyond the health audiences and having non-health people talk about it. Again, an experience from HIV where once it became a national security issue and went before the General Assembly of the UN, it totally changed who was interested.

So I think we've got to be smarter about how do we bring other allies into this, outside of the health arena, and keep linking it as opportunistically as we can to the things that we know people care about because ultimately, trying to get people to care about a non-event is going to always be an uphill battle.

DR. WAGNER: But you have helped us to better appreciate the opportunity that we have so that the work that we do might have effect and might be effective. Thank you all very much, a wonderful session.

(Applause.)